

## Questionnaire on volunteerism in care for patients with terminal conditions

We define 'volunteers' as every natural person performing an activity that is unpaid, non-obligatory, for another person, within an organisational framework other than an existing familial or social relationship, and not performed by the same person or for the same organisation as part of an employment contract or statutory appointment.

This questionnaire only concerns **the organisation**.

### Characteristics of volunteers within **your organisation**

#### 1. Are any volunteers active within **your organisation**?

- ☐ Yes  
☐ No      -> Go to question 22

#### 2. Are any volunteers active within **your organisation**, who do not belong to **your organisation**, but are put at your disposal by external organisations? (E.g., patient associations, etc.)

- ☐ Yes  
☐ No

#### 3. Are any of the volunteers active within **your organisation** (external or belonging to **your organisation**) involved in the direct patient care for patients with terminal illnesses? (E.g., cancer, chronic heart failure, Alzheimer's disease, etc.)

We define direct patient care as all activities which put the volunteer in direct contact with the patients or patients' relatives, for example: keeping the patients company, helping the patients with eating or drinking, offering the patients' relatives bereavement care, transporting the patients, etc.

- ☐ Yes  
☐ No      -> Go to question 22

#### 4. Please fill in the table below as accurately as possible.

Total of volunteers within the <b>organisation</b> :		
How many of these volunteers are involved in the direct patient care for patients with terminal conditions?		
How many of these volunteers involved in the direct patient care for patients with terminal conditions are volunteers belonging to <b>the organisation</b> ( <u>internal</u> ) and how many belong to <u>external</u> organisations?	Internal:	
	External:	

In the case of no external volunteers -> go to question 6

#### 5. Which organisations provide these external volunteers involved in direct patient care for patients with terminal conditions within **your organisation**?

Volunteers provided by an umbrella organisation that are not part of **your own organisation** are also considered external. Please provide the name, and if possible the address, website and e-mail of these organisations.

	Name	Address	Website	E-mail
1.				
2.				
3.				
4.				
5.				

## Volunteer tasks

6. Please indicate whether the tasks listed below are core tasks, secondary tasks or no tasks at all for your volunteers in direct patient care for patients with terminal conditions.

	Core task	Secondary task	No task
<i>(Please provide a response for each item below.)</i>			
<b>For the patient:</b>			
<b>a. Activities of Daily Living (ADL)</b>			
Washing the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dressing the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping the patients with toilet visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changing the patients (bodily hygiene)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping the patients with functional mobility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeding the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>b. Instrumental Activities of Daily Living (iADL)</b>			
Helping the patient with food preparation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing groceries for the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping the patient with phone usage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help the patient with household chores	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing the laundry for the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transporting the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping the patient with taking medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing finances for the patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>c. Psychosocial care for the patient</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>(Being there, listening, engage in conversation, stop by to see how the patient is doing, participating in leisure activities, building a bond with the patient, supporting the patient in the last moments of life)</i>			
<b>d. Being an intermediary between the <u>patient</u> and health care professionals</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>(Fulfilling a signalling function, being a confidant, make professional caregivers aware of issues or worries the patient might have, refer the patient to caregivers)</i>			
<b>e. Medical and nursing tasks</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>(Pain and symptom control, lifting and patient handling techniques, care for light wounds)</i>			
<b>f. Spiritual or existential care</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>(Talk about life and death, talk about religious subjects, dealing with regret and unattained life goals, dealing with the meaning of life, dealing with the fear of losing autonomy.)</i>			

**For the patients' RELATIVES (E.g., family, friends...):**

<b>g. Psychosocial care for the <u>patients' relatives</u></b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>(Being there, listening, engage in conversation, building a bond with the patients' relatives, supporting the relatives in their time of grief)</i>			
<b>h. Being an intermediary between the <u>patients' relatives</u> and health care professionals</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>(Fulfilling a signalling function, being a confidant, make professional caregivers aware of issues or worries the relatives might have, refer the relatives to caregivers)</i>			

## Barriers to volunteering

7. To what extent are the following organisational barriers a limitation to the volunteerism in **your organisation?**

<i>(Please provide a response for each of the barriers listed below)</i>	No barrier	Small barrier	Large barrier
<b>a. The financial costs of having a volunteering force for <b>the organisation</b></b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>b. The time investment a volunteering force requires</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>c. Finding suitable volunteers</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>d. Finding/attracting new volunteers</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>e. The integration of volunteers into <b>the organisation</b></b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>f. Legal prescriptions and conditions governing the responsibilities of volunteers</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>g. Other, please specify:</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
.....			
<b>h. Other, please specify:</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
.....			

## Recruiting volunteers

8. Please indicate how important the selection criteria listed below are in recruiting volunteers for **your organisation**.

(Please provide a response for each of the items below)

	Not important	Rather unimportant	Neutral	Rather important	Very important
a. Motivation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Realistic expectations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Mental and emotional stability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Sense of responsibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Ability to function independently	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Personal values and norms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Relevant work experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Communication skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Availability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Problem-solving work ethic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Flexibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Discretion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. Tactfulness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. Other, please specify:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Which of the resources listed below, if any, does **your organisation** use to attract new volunteers?

(Please check any and all that applies.)

- ☐ a. Loose print (E.g., posters, pamphlets, flyers)
- ☐ b. Internal printed media (E.g., internal magazine or newspaper)
- ☐ c. External printed or non-digital multi-media (E.g., external magazine, newspaper or radio/TV)
- ☐ d. Digital media (E.g., **the organisation's** website, social media)
- ☐ e. Current volunteers are mobilized to recruit new volunteers
- ☐ f. The organisation's open day
- ☐ g. Other, please specify:

10. How are volunteers followed up after recruitment? Here we mean both critical as well as positive feedback for the volunteers.  
(Please check any and all that applies.)

- ☐ There is no specific evaluation or follow-up of the volunteers
- ☐ There is an observational internship
- ☐ There is a trial period, after which volunteers are evaluated
- ☐ There is one set follow-up moment per year
- ☐ There are multiple set follow-up moments per year
- ☐ There is an evaluation planned when there is specific reason for it
- ☐ Feedback is occasionally given
- ☐ Other, please specify: .....

11. How long do volunteers stay with **the organisation**, on average?

- ☐ Less than 6 months
- ☐ 6 to 12 months
- ☐ 1 to 2 years
- ☐ 2 to 5 years
- ☐ 5 to 10 years
- ☐ More than 10 years

## Volunteer training

12. Are your volunteers offered training?

This training may be given by **your organisation** itself, as well as by external organisations.

(Please check any and all that applies.)

- ☐ No, they are not offered training.  
→ Go to question 14.
- ☐ Yes, a one-time, obligatory training course is offered.
- ☐ Yes, a one-time, non-obligatory training course is offered.
- ☐ Yes, multiple, obligatory training courses are offered. (E.g., once or several times per year)
- ☐ Yes, multiple, non-obligatory training courses are offered. (E.g., once or several times per year)
- ☐ Other, please specify: .....

**13. Please indicate which of these subjects are covered in the offered training courses.**  
(Please check any and all that applies.)

- ☐ The vision and values of the organisation
- ☐ The care provision of the organisation (which care is provided, and who provides this care)
- ☐ The position and roles of the volunteers within care
- ☐ The needs of the volunteers
- ☐ Ethical aspects of volunteerism
- ☐ Guarding personal and professional boundaries
- ☐ Themes regarding specific patient groups (e.g., dementia, cancer, specific diseases)
- ☐ Ethical aspects (discretion)
- ☐ Basic knowledge and skills of palliative care (e.g., communication skills, the four pillars of palliative care, etc.)
- ☐ Advance Care Planning
- ☐ Lifting techniques
- ☐ (Hand)hygiene
- ☐ Other, please specify:

.....  
 .....  
 .....  
 .....

## Position of the volunteer in the organisation of care for patients

**14. Please indicate how often the items listed below are applicable today in the organisation of professional and voluntary care for patients with terminal conditions in your organisation.**

(Please provide a response for each of the items listed below.)

	Never	Rarely	Often	Always
a. The volunteers are <u>informed</u> on how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. The organisation requests the opinion of the volunteers on how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The organisation takes into account the opinion of the volunteers when making decisions on how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The volunteers have <u>decision rights</u> regarding how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. The volunteers are able to <u>make autonomous decisions</u> regarding how certain aspects of the (professional and voluntary) care for the patients are organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**15. Do volunteers come together as a separate group to discuss the organisation of (professional and voluntary) care?**  
(Please check any and all that applies.)

- ☐ Yes, together with the presence of one or more staff members
- ☐ Yes, without the presence of staff members
- ☐ No -> Go to question 17

**16. How often do the volunteers come together as a separate group to discuss the organisation of (professional and voluntary) care?**

Less than once per year	At least once per year	At least once every 6 months	At least once per month	At least once per week
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**17. Do volunteers take part in meetings in which the medical condition of patients is discussed?**

- ☐ Yes, systematically
- ☐ Yes, sporadically
- ☐ No

**18. Is there a separate briefing for volunteers on the medical condition of the patients?**

- ☐ Yes
- ☐ No

## Personal views on the position of volunteers in the organisation of care for patients

19. Please indicate whether, according to you, the items listed below should happen less, happen enough, or should happen more often in **your organisation**. By 'happen enough' we mean that you believe the situation is fine as it currently is. (Please provide a response for each of the items listed below.)

	Less	Enough	More
a. The volunteers are <u>informed</u> on how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. <b>The organisation</b> requests the opinion of the volunteers on how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. <b>The organisation</b> takes into account the opinion of the volunteers when making decisions on how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The volunteers have <u>decision rights</u> regarding how (professional and voluntary) care for the patients is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. The volunteers are able to <u>make autonomous decisions</u> regarding how certain aspects of the (professional and voluntary) care for the patients are organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Volunteer policy

20. Were the vision and policy regarding volunteers within **your organisation** documented in a written policy?

*By this we mean policy documents, official rules, etc.*

- ☐ Yes, since .... / .... / ..... and the last version dates from .... / .... / .....
- ☐ No, but a document is in preparation -> **Go to question 22**
- ☐ No, but we plan to -> **Go to question 22**
- ☐ No, and we don't plan to -> **Go to question 22**

**Should your organisation have a written policy document regarding volunteerism in your organisation, please send us a copy of it together with this questionnaire using the attached post-paid envelope.**

21. Who was consulted during the creation of this policy document?

*(Please check any and all that applies.)*

- ☐ Board of directors
- ☐ Managing board
- ☐ Health care professionals (e.g., doctors, nurses, etc.)
- ☐ Patients
- ☐ Patients' relatives
- ☐ Volunteers
- ☐ Ethics committee
- ☐ Umbrella organisation
- ☐ Legal professionals
- ☐ Associations/institutions that support volunteerism
- ☐ Volunteer coordinator
- ☐ Insurance company
- ☐ Other, please specify: .....

## Information about yourself and **your organisation**

22. What is your function in **the organisation**?

- ☐ Director
- ☐ Department head
- ☐ Head nurse
- ☐ Volunteer coordinator
- ☐ Other, please specify: .....

23. How many full-time equivalent professional caregivers does **your organisation** have?

*By this we mean only the professional caregivers.*

*(E.g., doctors, nurses, psychologists, occupational therapists, speech therapists, physical therapists, etc.)*

- ☐ 1 – 10
- ☐ 11– 20
- ☐ 21 – 30
- ☐ 31 - 40
- ☐ 41 – 50
- ☐ > 50
- ☐ Not applicable

24. What is the care capacity of your organisation?  
(Please answer the question applicable to your organisation.)

a. Palliative Care Units and Nursing Homes:	Total beds:	.....	
b. Other organisations:	Total patients provided care for in the last week:	.....	

25. How many of your patients suffer from one or more terminal conditions? (E.g., cancer, chronic heart failure, Alzheimer’s disease, etc.)	<input type="radio"/> None
	<input type="radio"/> 0% - 25%
	<input type="radio"/> 26% - 50%
	<input type="radio"/> 51% - 75%
	<input type="radio"/> 76% - 100%

26. If you would like to make any additional remarks concerning certain responses on this questionnaire, you can do so below. This space can also be used to make any other remarks concerning this study or questionnaire.

**Reminder: Please send us a copy of your written policy documents**

Next to your answers to this questionnaire, we would also like to analyze the existing official policy regarding volunteers and volunteerism. To be able to do this, we request that you send us any and all types of written policy documents regarding volunteers that are present in your organisation in the attached post-paid envelope. All responses are processed anonymously.

Thank you very much for your participation.